On Target

Informing Indiana About Disability Issues Indiana Governor's Council for People with Disabilities July 2009

Volume 22 Number 6

Health care reform on the horizon

President Obama has signed an Executive Order creating a White House Office of Health Reform, signaling the administration's commitment to passing a health reform policy this year. The Office is headed by Nancy-Ann DeParle, who is responsible for coordinating health reform policy within the White House and federal agencies, as well as working with Congress to secure the passage of health reform legislation.

The Obama administration said it is committed to working with Congress to pass comprehensive health reform to control rising health care costs, guarantee choice of doctors, and assure high-quality, affordable health care for all Americans. The administration said it believes health reform should, among many things:

- Reduce long-term growth of health care costs for businesses and government.
- Protect families from bankruptcy or debt due to health care costs.
- End coverage barriers for people with pre-existing medical conditions.
- · Improve patient safety and quality of care.

President Obama has set general principles for Congress to develop reform legislation. Several congressional committees with jurisdiction over health reform issues have held hearings and set an ambitious goal of House and Senate passage before the August recess. However, there is no consensus on a number of significant issues, such as whether a public plan should be included and how to pay for overall reform.

Key health care policy issues affecting people with disabilities will include physician and dentist training on how to provide appropriate medical treatment for persons with disabilities; expanding Medicaid eligibility; and improving long-term services and supports including medical, social, personal care and supportive services.

The Arc, United Cerebral Palsy (UCP) and other disability organizations collaborated to develop the following recommendations for health care reform legislation:

- Ensure the private insurance system covers all Americans so that Medicaid and Medicare are not the only coverage options for people with disabilities.
- Incorporate long-term services and supports by including the CLASS Act and Community Choice Act.
- Strengthen the Medicaid program so that it provides accessible, high-quality health care services to people with disabilities who are enrolled in the program.
- Increase the education of physicians and dentists. Amend the Public Health Services Act to require medical schools, dental schools and residency programs to

include competency and clinical skills training for providing care to patients with disabilities.

In April, DeParle hosted a forum where approximately 30 invitees representing various segments of the health care community discussed options and strategies to enact health care reform in this Congress. The Disability Policy Collaboration, The Arc and UCP were active participants in this discussion, stressing the need for long-term services and supports to be part of health care reform, as well as the need for funding for home- and community-based services.

"The biggest challenge [for individuals with severe developmental disabilities] is long-term care or long-term services and supports. It is extremely expensive. Significant reform is necessary to make good fiscal decisions and good people decisions. There is pending legislation, like the Community Choice Act, that will shift us from institutions," said Paul Marchand, director of The Arc — Disability Policy Collaboration.

In addition to long-term supports and home- and community-based services, advocates also stress the need for health care reform to include mental health services, durable medical equipment and assistive technology.

The Consortium for Citizens with Disabilities (CCD), a coalition of various disability organizations including The Arc and UCP, has released a set of guiding principles to assess all current and forthcoming health care reform proposals from a disability perspective. According to CCD, health care reform must comply with the following principles to be fully inclusive for people with disabilities and their families:

- **Non-discrimination**: Allows all people with disabilities and their families the ability to fully participate in the health care system.
- Comprehensiveness: Provides access to benefits that offer a comprehensive array of health, rehabilitative, assistive device and support services across all service categories and sites of service delivery.
- **Continuity:** Provides access to health care that responds to long-term needs and offers continuous care to help treat and prevent chronic conditions.
- Appropriateness: Assures that comprehensive health, rehabilitative and long-term support services are provided on the basis of individual need, preference and choice.
- **Equity:** Provides equal access to health coverage programs and does not burden people with disabilities and their families with disproportionate costs.
- **Efficiency:** Provides access to health care that is effective and high quality with minimal administrative waste.

Visit www.healthreform.gov for additional information from the Obama administration on the nation's health reform, including a blog from Nancy-Ann DeParle and a forum for public discussion. For information from a disability standpoint, visit the CCD's Web site at www.c-c-d.org.

Wal-Mart to increase accessibility

Earlier this year, the Civil Rights Division of the U.S. Department of Justice entered into a settlement agreement with Wal-Mart Stores, Inc. under the Americans with Disabilities Act to improve access for people with disabilities at Wal-Mart locations nationwide. The issue was sparked after several complaints were filed accusing various Wal-Mart stores of declining to make modifications to its current policies and procedures for people with disabilities.

The agreement requires Wal-Mart to make several changes to current rules and practices, including:

- Discontinue discrimination against people with disabilities, such as denying people who are accompanied by service animals an equal opportunity to shop.
- Enhance current assistance practices for people with disabilities, such as helping customers locate, lift and carry items.
- Position Wal-Mart's new service-animal policy on its Web site and in all employee areas.
- Improve employee practices regarding assisting customers who utilize service animals.
- Train store managers and greeters regarding their additional responsibilities to assist people with disabilities.
- Establish a toll-free hotline to receive complaints and a grievance procedure to investigate complaints, and take appropriate actions to resolve issues.

For more information, visit www.ada.gov/walmart.htm.

New cross-disability coalition meets with presidential staff

A new national disability-led coalition, Justice for All Action Network (JFAAN), recently met with government officials Kareem Dale, special assistant to the president for disability policy, and Jeff Crowley, director of the National AIDS Office and senior adviser on disability issues within the Domestic Policy Council. Eleven members of JFAAN attended to discuss common policy issues concerning the disability community. Ron Brown, from Indiana, is the second vice president of the National Federation of the Blind and was one of the attending members.

"I believe the most positive message we brought [to the meeting] was that the Network is represented by organizations led by people with disabilities. Therefore, the group is a cross-section that represents the disability community well. Everyone got a chance to bring issues to the table," said Brown. "The meeting laid the foundation for ongoing communication with the disability community."

Policy topics discussed at the meeting included health care, home- and community-based and long-term services and supports, improved housing, technology,

transportation and education policy. A focus of the education policy discussion was addressing problems identified in a recent report by the Government Accountability Office documenting widespread abuse of children in schools through aversives, restraint and seclusion. Also addressed was the need for policymakers to regularly seek the input of disability rights organizations led by individuals with disabilities.

If you are interested in signing up for the JFAAN Listserv, please visit http://jfactivist.typepad.com/jfactivist and type your e-mail address in the space provided on the left. The Network conducts weekly calls and has initiated policy workgroups on employment, health care reform and grassroots organizations. If you are interested in participating in the calls or joining one of the groups, please contact Sarah Peterson, grassroots organizer and Justice For All moderator, at jfa@aapd.com.

2009 National Disability Seminar unites advocates

In late April, hundreds of disability advocates from around the nation discussed a wide range of public policy issues affecting people with disabilities and their families at the 2009 Disability Policy Seminar in Washington, D.C.

The seminar's theme, "A New Era: Embracing Opportunities in the Face of Grave Challenges," explored the unique challenges and opportunities facing the 111th Congress and Obama administration brought about by the 2008 election results and the economic crisis.

The seminar delivered public policy updates and generated recommended action steps for those issues relevant to the disability community, including:

- Education: Disability advocates are working to ensure that any potential legislative changes to the No Child Left Behind Act do not negatively impact students with disabilities. Advocates also support fully funding the Higher Education Act and increasing funding for the Individuals with Disabilities Education Act (IDEA).
- Housing: Advocates encourage an increase of at least \$25 million for the Section 811 Supportive Housing for Persons with Disabilities program, as well as support of President Obama's request for \$1 billion for the National Affordable Housing Trust Fund.
- Long-term Services and Supports: In addition to the Community Choice Act and the CLASS Act, advocates support the Empowered at Home Act (S. 434), the Direct Support Professionals Fairness and Security Act (H.R. 868) and the Ending the Medicare Disability Waiting Period Act (S. 700/H.R. 1708).

Seminar attendees also had an opportunity to visit Capitol Hill, meet their congressional delegation and deliver a unified message that disability benefits and services are top priorities.

For more information, visit www.thearc.org and click on "Public Policy."

New ACAA requirements improve access for travelers with disabilities

New requirements were recently added to the Air Carrier Access Act (ACAA), passed in 1986, to further address accessibility issues for travelers with disabilities:

- Foreign carriers: ACAA coverage has been extended to include airlines based outside the United States.
- Aircraft accessibility: Depending on the size of the aircraft, the ACAA requires accessible lavatories, wheelchair stowage and high-contrast captioning for informational audiovisual displays.
- **Terminal accessibility:** Airport terminals must ensure an accessible path from the gate to the boarding area and to systems of inter-terminal transportation (i.e., moving sidewalks and shuttle vehicles).
- **Airplane accommodations:** Passengers with disabilities are permitted to use FAA-approved portable oxygen concentrators in the aircraft cabin. This may require 48 hours advance notice.
- **Communication devices:** Passengers with hearing impairments have access to text telephones, voice relay or other available technology.
- Assistance animals: Passengers traveling with emotional support animals or psychiatric service animals must provide documentation and give 48 hours advance notice before flight.

Visit <u>www.swdbtac.org</u> and click on "Disability Law Index" to review the full set of updated ACAA regulations.

Proposed Community Choice Act would increase community-based care

The Community Choice Act (SB 683), sponsored by U.S. Sen. Tom Harkin (D-IA), would fundamentally change the nation's long-term care system. The legislation would afford individuals eligible for nursing or intermediate-care facility services the opportunity to choose community-based attendant services instead of institutionalized care. The policy would also let the user choose where the services will be delivered.

The United States' current long-term care system is primarily funded by Medicare and Medicaid, which were not originally designed to meet people's long-term care needs. Medicaid is required to provide nursing-home services, but community-based services are optional. Sixty-seven percent of Medicaid's long-term care dollars pay for institutional services, while the remaining 33 percent must cover all the community-based waivers and optional programs.

Community-based services include assistance with daily living activities (eating, grooming, bathing), instrumental activities (meal planning and preparation, managing finances) and health-related functions in a person's home, rather than an institution.

Services are based on need, rather than diagnosis or age, are provided in home or community settings, and are selected, managed and controlled by the consumer of the services. For consumers not able to direct their own care independently, the Community Choice Act would allow a friend, family member or guardian to assist.

The Community Choice Act would cover individual transition costs from a nursing facility to a home setting, serve individuals with incomes above the current institutional income limitation, and provide quality assurance programs that promote consumer control and satisfaction.

Visit www.passthecommunitychoiceact.org to learn more.

Of Note

Free wellness passport for Hoosier kids

A free wellness passport for Indiana kids is now available to help families track and store their children's medical information and share it with health care providers. The new tool allows families to easily provide medical information to all physicians quickly and accurately, rather than contacting each physician individually when a child's medical information has changed. The passport is free to download. Visit http://earlychildhoodmeetingplace.indiana.edu and click on the Family Information and Resources tab.

Free pass for parks and recreation areas

People with disabilities can now receive a free lifetime Access Pass from the National Park Service (NPS) that waives entrance and standard amenity fees at federal recreation sites. With the Access Pass, the pass holder and up to three adult guests receive free admission into locations that charge per-person fees. Per-vehicle fees are also waived for the pass holder and his/her passengers. Access Passes can only be obtained in person at eligible locations and are not transferable. To learn more, visit www.nps.gov/fees_passes.htm.

Claypool named disability director for Health and Human Services

The Department of Health and Human Services (HHS) has named Henry Claypool as director of the Department's Office on Disability. Claypool will serve as the primary advisor to the HHS secretary on disability policy. He'll also oversee the implementation of all HHS programs and initiatives for Americans with disabilities. Claypool has extensive experience as an advisor to federal, state and local governments, and he most recently served as policy director for a managed-care agency supporting people with disabilities in New York City. To contact HHS, call (877) 696-6775 (toll free, voice).

Conference date correction

The dates for the 2009 Conference for People with Disabilities were listed incorrectly in the June "On Target." The Conference, themed "Invest in People and Share in the Profits," will take place Monday, Nov. 16, and Tuesday, Nov. 17, at the Hyatt Regency in downtown Indianapolis.

On Target is a monthly publication of the Indiana Governor's Council for People with Disabilities. We welcome your suggestions for newsletter content and ideas concerning the actions of the Council. on target is made available in accessible formats upon request.

ADA CELEBRATES ITS 19TH ANNIVERSARY

SPECIAL INSERT

Hoosiers make a difference

July 26 marks the 19th anniversary of the Americans with Disabilities Act (ADA) of 1990 — the world's first comprehensive civil rights law for people with disabilities. Signed by former President George H. W. Bush, the ADA prohibits discrimination against people with disabilities in a variety of areas, including employment, public services, public accommodations and telecommunications. To continue implementing the ADA throughout Indiana, Hoosiers with disabilities and other advocates are making great strides in communities across the state.

Ongoing advocacy in Orange County

One advocate in Orange County, Dee Wheat, has made a difference for people with disabilities in her community. Wheat, who uses an iBot wheelchair, works daily to educate the public about the concerns of people with disabilities. She focuses most of her efforts on increasing accessibility of facilities and services.

"You can improve the availability of various things, such as transportation and employment, for people with disabilities. But, if people can't get to them and access them, then those things may as well not be there," said Wheat.

Among her successes, Wheat got the local jail, grocery store and school to add accessible parking spaces to their parking lots. She continues to work with local police to ensure laws against parking illegally in accessible spaces are enforced. She also works with local festivals to increase accessibility. During many festivals, streets and other areas have been blocked off to cars, which also posed a barrier for patrons in wheelchairs, according to Wheat. Some improvements have been made, including the addition of new sidewalks and curb cuts.

To address accessibility problems at various facilities, Wheat says she reaches out to staff and management personnel. She also contacts legislators on a regular basis to advocate for legislation that affects the disability community. And she writes on several blogs to help voice the concerns of people with disabilities.

The iBot chair also helps start conversations, according to Wheat, because it's an interesting wheelchair that can climb stairs, jump curbs and even balance on two wheels. "I use whatever opportunities I have to educate and advocate," said Wheat.

Wheat, a photographer who takes many pictures for marching bands, isn't afraid for her voice to be heard. Many advocates are hesitant to speak up because they don't want to upset anyone, said Wheat. "Everybody wants to be liked. But to be an advocate, you

have to decide if you want to be liked or respected. Some days, you just can't be both," said Wheat.

Post office accessibility in North Manchester, Ind.

In North Manchester, Ind., Terry Carpenter and Susan Dockter, both advocates for people with disabilities, are working with the local post office to make the facility accessible for people with mobility impairments. The post office is in a historic building that doesn't currently comply with the ADA, so patrons who use wheelchairs cannot get into the post office. Instead, they have to go around to the back of the office where one of the employees must meet and assist them.

In March of this year, the advocates conducted an assessment of the facility by working with Fifth Freedom, a statewide grassroots advocacy organization funded by the Governor's Council for People with Disabilities that strives to make Indiana communities more accessible for people with disabilities. The group found several problems, including:

- To enter the post office, patrons must use stairs, as a ramp is not available.
- Accessible parking isn't marked.
- The entry door isn't wide enough to meet ADA standards.
- The counter where patrons prepare their mail is higher than 34 inches, which is against ADA standards.
- Postage materials, including envelopes and labels, are not in an accessible area.

The group sent a letter offering assistance with removing the physical barriers in the post office and is now waiting to hear back from the postmaster. The advocates are also waiting to hear from local legislators about setting up a meeting to address the issue.

Closed-captioning in Lake County libraries

In Lake County, the Northwest Indiana Hearing Loss Support Group advocated to bring closed-captioning to films offered by the Lake County Public Library branches. The group also worked with Fifth Freedom to contact the library and provided recommendations for making adjustments to its closed-captioning policy.

According to Fifth Freedom, people with hearing impairments who visited the library claimed that closed-captioning requests had not been honored. One individual called the library ahead of time to request closed-captioning be turned on, but the accommodation wasn't made. And, the individual claimed that some of the library staff didn't know how to turn on closed-captioning.

The group provided the library with the following recommendations:

- Create a standard form to be filled out by the staff member who takes a request for captioning from a patron.
- Train all audio/visual staff (and all others who will be running film) on how to use captioning.

- Identify which films are equipped with captioning in advertisements, the library newsletter, the library Web site and all fliers pertaining to scheduled films. Use the phrase "captioning available" or "CC" to properly identify which films provide captions.
- Create a written policy that specifies who is responsible for all the steps in the process, including: identifying captioned films, advertising that captioning is available, keeping track of requests for captioning, training employees and turning on the captioning. Make this policy available to the public so that patrons can make inquiries or, if needed, file complaints.

The group has worked with Dawn Mogle, head of audio/visual services at the library branches, to discuss opportunities for increasing closed-captioning. Although many of the films simply don't have captions, the libraries have agreed to train staff members to operate closed-captioning for the films that do provide captions.

In addition, the Hearing Loss Support Group is reaching out to movie theaters in the area to advocate for more show times with closed-captioning. The group is partnering with local advocates and people with hearing impairments to write letters to the various theaters, particularly to request that closed-captioning be available more often. In many theaters, the service is only available two days per month.

The Governor's Council for People with Disabilities congratulates these advocates and so many others who have made a difference in their communities.

Looking forward to next year!

Next year will mark an exceptional milestone in the history of the Americans with Disabilities Act (ADA), which will celebrate its 20th anniversary on July 26, 2010. The Governor's Council encourages Hoosier advocates to begin developing plans to commemorate the monumental day.

Much like March Disability Awareness Month, advocates can reach out to their local communities to build awareness about the ADA. Many of the materials and resources provided by the Governor's Council for Disability Awareness Month can be easily adapted and tailored to spread the word about the ADA. Visit www.indianadisabilityawareness.org and click on "Materials Library" to find ideas and download activity packets.

The Great Lakes ADA Center will also host a poster contest next year to build awareness. Participants will submit a poster design that illustrates the theme "How the ADA has Changed the Face of Your Community." More information will be posted at a later date at www.adagreatlakes.org.

ADA Amendments Act now in effect

On Sept. 25, 2008, the ADA Amendments Act was signed into law to restore the original intentions of the Americans with Disabilities Act (ADA) of 1990. One of the most important goals of the ADA was to end discrimination of people with disabilities by employers. However, the courts misinterpreted the language and purpose of the legislation in a number of significant cases involving employment, which excluded many individuals from its protections.

The Amendments Act reverses these narrow court interpretations so future cases will not use those decisions as a precedent. The intention is to make it easier for an individual seeking protection under the law to establish that he or she has a disability within the meaning of the ADA.

The Amendments Act retains the ADA's basic definition of "disability" as an impairment that substantially limits one or more major life activities, a record of such an impairment, or being regarded as having such an impairment. However, it changes the way these statutory terms should be interpreted so that more individuals with disabilities are covered by the ADA's protections.

Organizations and government entities are making changes to comply with the Amendments Act. The U.S. Equal Employment Opportunity Commission recently voted to revise its regulations to conform to the law, recognizing the need for Americans with disabilities to fully participate in the workforce.

The ADA Amendments Act went into effect Jan. 1, 2009, meaning the Act applies only to claims brought forth on or after that date. However, some attorneys for employees with disabilities are arguing that the Act should be applied retroactively, which would mean it applies to all claims pending as of Sept. 25, 2008.

Heather McCabe, executive director of the Hall Center for Law and Health at Indiana University, collaborated with the university's Center for Health Policy to produce a brief titled "New ADA Amendment Benefits People with Disabilities and Businesses." This brief outlines the original ADA, discusses some of the important court decisions and addresses the anticipated impact of the Amendments Act on both individuals and businesses. To view the brief, visit www.indylaw.indiana.edu and click on "News & Events."

ADA Resources

For Hoosiers seeking information about the Americans with Disabilities Act, there are two primary resources serving Indiana:

Great Lakes ADA Center:

Provides information, materials, technical assistance and training on the ADA, serving six states: Illinois, Indiana, Michigan, Minnesota, Ohio and Wisconsin. Visit www.adagreatlakes.org or call (312) 413-1407 (voice/TTY).

ADA Indiana:

Promotes the implementation of the ADA throughout the state. Visit

New census statistics about Americans with disabilities

In light of the Americans with Disabilities Act (ADA) anniversary, the U.S. Census Bureau recently released new population statistics about people with disabilities. Some highlights include:

- 41.2 million people in the United States have some level of disability.
- 13.3 million people between 16 and 64 years of age have reported a medical condition that makes it difficult to find a job or remain employed.
- 46 percent of people ages 21 to 64 who have some type of disability were employed in the past year.
- 59 percent of people ages 21 to 64 are employed and have difficulty hearing.
- 41 percent of people ages 21 to 64 are employed and have difficulty seeing.
- 12 percent of people ages 25 to 64 with a non-severe disability live in poverty.
- \$28.2 billion is the amount of compensation veterans received for service-related disabilities in fiscal year 2007.
- 98.5 percent of transit buses were ADA lift- or ramp-equipped, as of 2006. This is an increase from 61.7 percent in 1995.

To review the full report and more statistics, visit www.census.gov and click on the Americans with Disabilities Act icon in the top left corner.

History of the ADA: The Disability Rights Movement

The Americans with Disabilities Act (ADA) was passed in 1990 and became a significant landmark in people with disabilities' quest for equal rights. In addition to the ADA, several people, organizations and events influenced the disability rights movement. These are just some of the highlights:

- 1956 Congress passes the Social Security Amendments of 1956, creating a Social Security Disability Insurance (SSDI) program for workers with disabilities ages 50 to 64.
- 1963 President Kennedy, in an address to Congress, calls for a reduction "over a number of years and by hundreds of thousands, [in the number] of persons confined" to residential institutions, and he asks that methods be found

"to retain in and return to the community the mentally ill."

- 1964 The Civil Rights Act is passed, but does not cover people with disabilities in its discrimination protections.
- 1965 Medicare and Medicaid are established through passage of the Social Security Amendments of 1965.
- 1968 The Architectural Barriers Act is passed widely considered to be the first disability rights legislation and mandates that federally constructed buildings and facilities be accessible to people with physical disabilities.
- 1970 The Developmental Disabilities Services and Facilities Construction amendments are passed, containing the first legal definition of developmental disabilities (DD).
- 1971 The National Center for Law and the Handicapped is founded at the University of Notre Dame in South Bend, Ind., becoming the first legal advocacy center for people with disabilities in the United States.
- 1972 The Center for Independent Living (CIL) is founded in Berkeley, Calif. Generally recognized as the world's first independent living center, the CIL sparks the worldwide independent living movement.

Passage of the Social Security Amendments of 1972 creates the Supplemental Security Income (SSI) program.

- 1973 The Rehabilitation Act is passed, confronting discrimination against people with disabilities for the first time. Section 504 of the Act prohibits programs receiving federal funds from discriminating against "otherwise qualified handicapped" individuals.
- 1975 Congress reauthorizes the Developmentally Disabled Assistance and Bill of Rights Act (originally passed in 1970), extending funds to protection and advocacy programs in all states and establishing rights for people with developmental disabilities. The Act also funds state councils and university-affiliated programs. In Indiana, these programs include the Indiana Governor's Council for People with Disabilities, Indiana Protection and Advocacy Services and the Indiana Institute on Disability and Community.

The Education for All Handicapped Children Act is passed, establishing the right for children with disabilities to receive a public school education in an integrated environment.

- 1982 The Telecommunications for the Disabled Act mandates telephone access at important public places, such as hospitals and police stations, for people who have hearing impairments.
- 1984 The Voting Accessibility for the Elderly and Handicapped Act mandates that registration and polling locations for federal elections be accessible for people with disabilities.
- 1986 The Air Carrier Access Act is passed, prohibiting airlines from discriminating against people with disabilities.
- 1988 The Fair Housing Amendments Act adds people with disabilities to those groups protected by federal fair housing legislation.
- 1990 The ADA is signed by President George H. W. Bush on July 26.

- 2000 The Developmental Disabilities Assistance and Bill of Rights Act of 2000 reauthorizes state programs for people with developmental disabilities.
- 2004 The Individuals with Disabilities Education Improvement Act is passed to provide greater educational opportunities to children with disabilities.
- 2008 The ADA Amendments Act is signed into law by President George W. Bush on Sept. 25 to restore the original intentions of the ADA.

To learn more about historical moments in the disability movement, visit the Museum of disABILITY History online at www.museumofdisability.org.